Co-design of a unified international aphasia awareness campaign

Claire Bennington_{1,2}*, Ciara Shiggins_{1,2,3,4}, Jytte Isaksen_{5,6}, Emma Beesley₁, Kim Beesley₁, and Sarah J. Wallace_{1,2,3}

1 Queensland Aphasia Research Centre, School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, Australia 2 Surgical Treatment and Rehabilitation Service (STARS) Education and Research Alliance, The University of Queensland and Metro North Health, Brisbane, Australia 3 Centre of Research Excellence in Aphasia Recovery and Rehabilitation, Australia 4 School of Health Sciences, the University of East Anglia, Norwich, United Kingdom 5 Department of Culture and Language, University of Southern Denmark, Odense, Denmark

6 Neurorehabilitation Research and Knowledge Centre, Rigshospitalet, Copenhagen, Denmark



Queensland Aphasia Research Centre

Introduction

- Low aphasia awareness is an **international problem**.
- Despite numerous campaigns designed specifically to raise aphasia awareness, more than 20 studies across 20 countries have demonstrated that awareness of aphasia is **persistently low** (Bennington et al., in preparation; Bennington et al., 2024).
- Simmons-Mackie et al., (2020) identified **possible reasons** for the **lack of campaign** \bullet success:
 - campaigns have **not had a unified and compelling message**
 - ii. campaigns have not been coordinated across organisations and campaigns

Results

- The **desired outcome** of the campaign was: "One day the world's population will understand aphasia and all people with aphasia will be treated with respect and kindness."
- This outcome directed all other campaign elements, including the **target audience** (the **general public**), **messages** (an understanding of what aphasia is/is not and its impact) call/s to action, and a tag line (Recognise Respond Respect). See Figure 2.
- A multistep plan for how best to operationalise the campaign was co-developed. This included **seeking funding** to develop the campaign assets, **translating the**
- iii. campaigns tend to target people who are already aware of aphasia
- iv. campaigns are **not informed by theory or research**
- v. people living with aphasia and health-care professionals are **not always** included in their design
- vi. the **impact of campaigns** has **not been evaluated.**
- This study **aimed** to **co-design a blueprint** for a **unified, international aphasia** awareness campaign and a strategy to operationalise it, with the ultimate aim of raising awareness of aphasia globally.

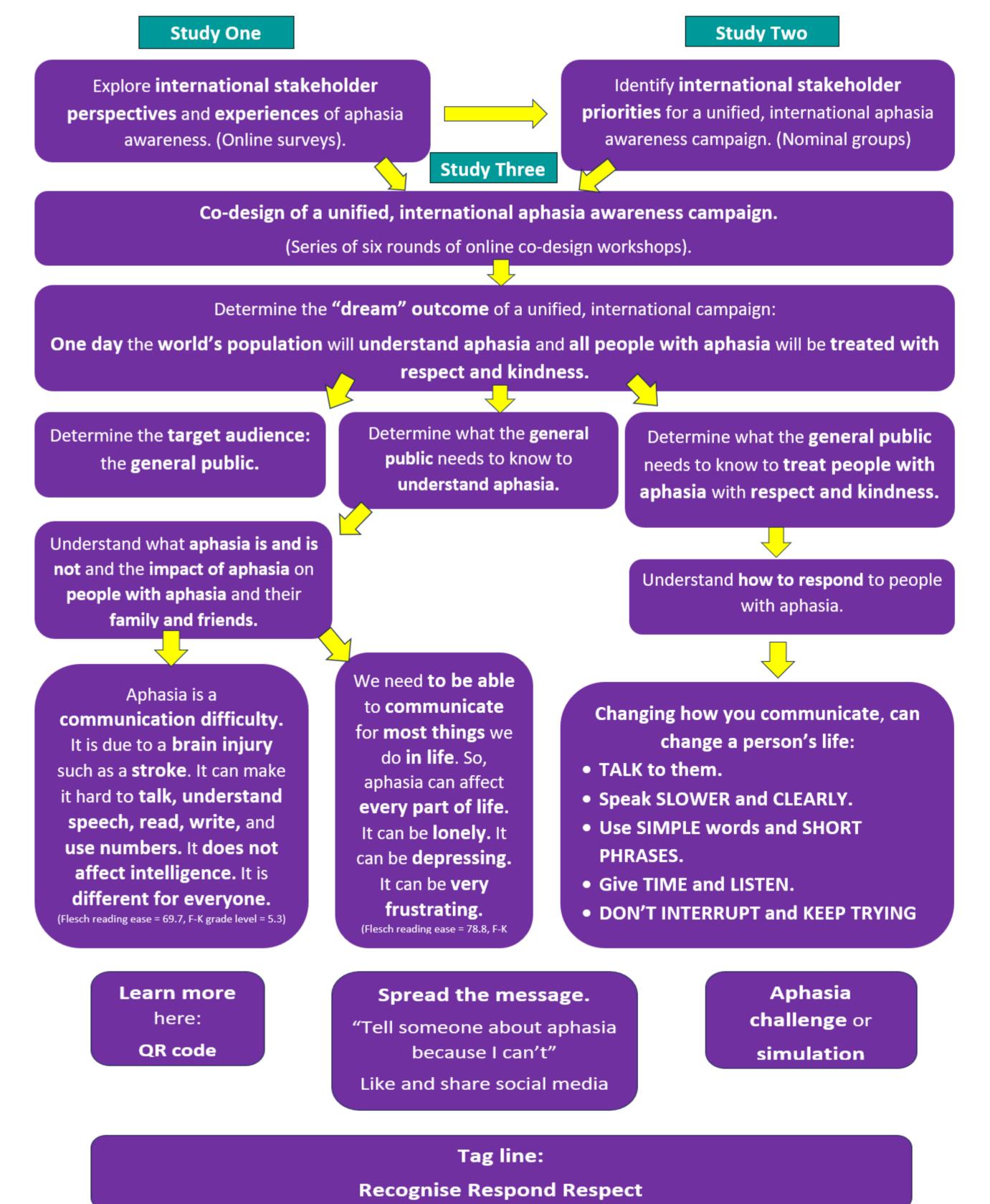
Method

This study used a **Patient and Public Involvement (PPI) approach using co-design** methods (McMenamin et al., 2022):

- A team of people with different backgrounds and expertise from seven countries, four continents and eight time zones, collaborated in the co-design process.
- This **international co-design team** comprised: ۲
 - three **people with lived experience of aphasia**
 - ii. three representatives of national and international aphasia, stroke, and neurorehabilitation organisations, and
 - iii. three **people with media, marketing, health promotion and** implementation science expertise.
- The team collaborated in **a series of 18 online iterative workshops** (6 rounds of 3 \bullet workshops to manage the time zones). See Figure 1 for workshop outline.

campaign into other languages and identifying campaign champions in as many countries as possible to help **promote**, **distribute**, and **evaluate the campaign**.

Figure 2: Outcomes of the Iterative Co-design Decision Making Process



- The workshops were informed by two previous studies (Bennington et al., 2024) \bullet and Bennington et al., in preparation).
- **Involvement** was reported per the **Guidance for Reporting Involvement of** \bullet Patients and the Public (GRIPP) 2 shortform (Staniszewska et al., 2017).

Figure 1: Workshop Outline



Conclusions

- A blueprint for a culturally sensitive, unified, international aphasia awareness **campaign**, and a **plan to operationalise it** were co-designed.
- Future directions include **co-development of the campaign and materials**, **including** ulletmulti-lingual translation, implementation, and scale up.

References

Scan the **QR code** for a **copy of the poster** with the **complete reference list.**



Acknowledgements

message Discussion re. format and design of the campaign

A research centre of the



THE UNIVERSITY Metro North OF QUEENSLAND Health AUSTRALIA CREATE CHANGE



With thanks to Dr Tanya Rose for her advice in the planning stage of this project. Claire Bennington is supported through an Australian Government Research Training Program Scholarship Emma and Kim Beesley are funded by the Queensland Aphasia Research Centre, which is funded by the Bowness Family Foundation and an anonymous donor Our co-designers with lived experience are funded by a Health Translation Queensland Consumer and Community Involvement (CCI) Microgrant Sarah J. Wallace is supported by the National Health and Medical Research Council under an Emerging Leadership Investigator Grant (1175821).

***Contact:** Claire Bennington **Email:** <u>c.bennington@student.uq.edu.au</u> **:** @ClaireBenningt4

CRICOS Provider 00025B

Queensland Aphasia Research Centre

Surgical, Treatment and Rehabilitation Service (STARS) 296 Herston Road, Herston QLD 4029

T: +61 7 3365 7595 **E**: qarc@uq.edu.au **W**: shrs.uq.edu.au/qarc